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ABSTRACT

This 60-item bibliography, a compilation of abstracts of books, articles, handbooks, conference proceedings, and newsletters published from 1978 through 1989, addresses various aspects of groups, programs and other self-help resources for parents and other family members of people with disabilities. Literature in the first section provides guidelines for group advocacy and working effectively within existing service delivery systems. The second section identifies resources concerned with key factors in group success or failure, the importance of clear communication, and several specific types of self-help groups. Section 3 focuses on parent empowerment in group leadership, providing advice for professionals working with parent support groups and discussing relations between parents and professionals in such groups. The role of professionals as consultants, sponsors and liaisons to support groups is explored in the resources listed in Section 4, with an emphasis on the importance of equality and mutual self-respect between self-help consumers and professionals. Much of the literature cited in the fifth section consists of research articles regarding parent support groups, including findings from evaluations of group effectiveness and descriptions of the parent mutual aid process. A final section covers effects of group participation, members' reasons for seeking support, and members' perceptions of help received from group involvement. (PB)

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DEVELOPING AND MAINTAINING MUTUAL AID GROUPS FOR PARENTS AND OTHER FAMILY MEMBERS:

AN ANNOTATED BIBLIOGRAPHY

Research and Training Center on Family Support
and Children's Mental Health
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DEVELOPING AND MAINTAINING MUTUAL AID GROUPS FOR PARENTS AND OTHER FAMILY MEMBERS:

AN ANNOTATED BIBLIOGRAPHY

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DEVELOPING AND MAINTAINING MUTUAL AID GROUPS FOR PARENTS AND OTHER FAMILY MEMBERS: AN ANNOTATED BIBLIOGRAPHY

Introduction

This annotated bibliography was developed to provide a relevant and practical resource for parents and other family members as well as for professionals who work with them. The bibliography is a compilation of books, articles, handbooks, conference proceedings, and newsletters. It contains information about various aspects of groups and programs as well as many other types of self-help groups and organizations.

The original focus of the literature search was on support groups and programs for parents of children who have serious emotional disabilities. The search was expanded to include all types of parent support groups. However, the relatively small pool of literature pertaining to mutual aid in parent support groups required this search to be expanded further to include information about various types of self-help groups. As a result, this literature review contains a comprehensive overview of the mutual aid process occurring in parent support and self-help groups in a variety of populations.

The content of the bibliography primarily concentrates on parent support groups because of the value placed on family-centered services. We believe that services should be driven by family members' needs and preferences and that children and their families should be the primary sources of information and participation in any decisions affecting their lives (Research & Training Center Proposal Summary, 1989, p. 19).

Parent support groups and programs are the focus of three sections in the annotated bibliography (I, III, and V). A distinction is made between parent support *groups* and *programs*. In this bibliography, parent support programs are typically one component of a mental health or residential treatment program for children and generally are conducted in a parent education format. Mutual support may or may not evolve among parents who participate in such programs. On the other hand, parent support groups are based on giving and receiving mutual support.

The terms self-help and mutual aid are used extensively throughout the bibliography and generally represent the language used by the particular author of the article or book. It is important to understand the ways in which these terms are used by the authors since different group processes or assumptions may be implied (Powell, 1982). Some authors make no distinctions between mutual aid and self-help (Chutis, 1983; Silverman, 1982; Yoak, Chesney & Schwartz, 1985). It should also be noted that mutual aid, mutual help, and mutual support are used in different places in the bibliography. For our purposes, no major distinctions are made between these terms. This appears to be consistent with much of the literature reviewed for the bibliography (i.e. Anglin, 1985; Lieberman & Borman, 1979; Pearson & Sternberg, 1986; Rappaport, et al., 1985; Silverman, 1980).

For the process of mutual aid to occur, a trusting and supportive environment must exist to enable the group to organize and coalesce to help themselves and each other. As a component of support groups, mutual aid is the actual *exchange* of assistance between people with similar circumstances (Silverman, 1980). Mutual aid may be preferable to the term self-help because it includes the notion of a shared exchange

and an emphasis on equality and competency, rather than on the need for group members to change. The notion of enhancing self empowerment through group interaction is a critical component of the mutual aid process (Reissman, 1985; Lemberg, 1984).

In contrast, self-help is emphasized by some authors as an alternative or complement to traditional, professionally-administered service agencies (Wollert, 1988). Self-help groups usually focus on empowering the individual to change personally undesirable patterns of behavior and/or thinking (Powell, 1987). In addition, these groups may occasionally request or receive assistance from professionals who assume group leadership or consulting roles (Powell, 1979). Conversely, mutual aid groups may include professionals as group members, with *membership* being their primary role.

The bibliography is organized into three major categories with regard to support or self-help groups: (1) organization and development of groups; (2) professionals' roles; and (3) benefits and descriptions of group participation. Each category is divided into two subcategories. The first is focused on parent support groups and programs and the second concentrates on self-help groups and organizations. The following format is used for the bibliography:

I. Organizing and Developing Parent Support Groups and Programs
II. Organizing and Developing Self-Help Groups and Organizations
III. Professionals' Roles in Parent Support Groups and Programs
IV. Professionals' Roles in Self-Help Groups and Organizations
V. Benefits and Descriptions of Participation in Parent Support Groups and Programs
VI. Benefits and Descriptions of Participation in Self-Help Groups and Organizations

Although the literature has been sorted into these categories according to primary content, there is a great deal of overlap across categories.

In the first section, *Organizing and Developing Parent Support Groups and Programs*, the authors provide guidelines for group advocacy and advice for working effectively within the service delivery system. Much of the literature in this section focuses on helping parents and professionals organize and sustain parent self-help support groups, although some authors report primarily on groups organized by and for parents (Pizzo, 1983; Nathanson, 1986; Fox, 1987; Reynolds and Shanahan, 1981). Specific issues include group maintenance and leadership.

Authors included in this section also discuss issues relevant to bereaved parents and parents of children with disabilities (Des Jardins, et al., 1980; Dickman & Gordon, 1985). This section also contains literature for parents who want to change the policies and systems affecting their children, including public schools, social and medical services, health care, residential centers, and various aspects of legislation (Hoppe, 1979; Donner & Fine, 1987).

The second section addresses *Organizing and Developing Self-Help Groups and Organizations*. Many of the topics presented in Section I are also discussed here, particularly with regard to advocacy-oriented activities and group leadership, process, and maintenance issues. One book provides information about ways to locate existing self-help organizations (Madara & Meese, 1986). A few of the authors (Lakey, no date; Lemberg, 1984; Lyon, 1988) stress the importance of clear communication between group members and positive group facilitation skills. Reasons for group success or failure are illustrated by one author (Lemberg, 1984). Several types of self-help groups are addressed in this section (bereaved spouses, individuals with specific medical problems, families of individuals with mental disabilities, adults with mental disabilities).

Much of the literature in the third section regarding *Professionals' Roles in Parent Support Groups and Programs* emphasizes parent empowerment in group leadership, although a few authors advocate professional involvement utilizing a parent education or training approach (Klass & Shinners, 1982; Lowenstein, et al., 1981). The often-debated philosophical gap between parents and professionals is discussed by several authors in this section. Authors provide pragmatic advice for professionals working with parent groups and urge them to refrain from assuming an "expert" or therapeutic role and to instead act as a group sponsor and facilitator (Klass & Shinners, 1982; Moore, 1983).

The idea of professionals as consultants, sponsors, and liaisons to support groups is shared by authors who address these issues in the section of the bibliography entitled *Professionals' Roles in Self-Help Groups and Organizations*. Wintersteen & Young (1988), Silverman (1982), and Chutis (1983) offer insightful ideas about the ways in which professionals can enhance the self-help process without dominating the group or usurping the power of its natural leaders. Most of the authors emphasize the importance of equality and mutual respect between self-help consumers and professionals.

The literature contained in the fifth section, *Benefits and Descriptions of Participation in Parent Support Groups and Programs*, covers a broad range of topics. Most of the research articles in the bibliography regarding parent support groups are contained in this section. Authors present findings from evaluations of group effectiveness and descriptions of the parent mutual aid process. Powell (1979) makes distinctions between help provided by other parents and by professionals. Some articles describe the specific needs of different groups of parents (Peach & Klass, 1987; Minde, Shosenberg & Hines, 1978; Kratochvil & Devereux, 1988; Yoak, Chesney & Schwartz, 1985). Other authors describe specific parent support programs (Peterson & Kelleher, 1987; Pearson & Sternberg, 1986; and Kagey, Vivace & Lutz, 1981) while Videka-Sherman (1982) discusses the effects of support group participation on parents.

In the section regarding *Benefits and Descriptions of Participation in Self-Help Groups and Organizations*, the authors provide information about the effects of group participation and members' reasons for seeking support (Lieberman & Videka-Sherman, 1986; Shulman, 1986; Spiegel, 1982; Young & Williams, 1988). Members' perceptions of the help received from the group is also discussed in several articles (Biegel & Yamatani, 1987; Maton, 1988). Elements of the self-help process and components of specific self-help groups are also described. Most of the research articles regarding self-help groups and organizations are contained in this category.

The bibliography includes articles based on research and on descriptions of parent support groups and programs; those based on empirical research are identified by an asterisk (*) throughout the bibliography. More empirical research is needed to focus on the mutual aid process in support groups. Family members should be encouraged to share their support group experiences through collaborative writing efforts with other parents or professionals and through participation in research efforts. Parents are valuable resources for each other and organized groups are an important means of survival, mutual support, and change in the service delivery system.

SECTION I: Organizing and Developing Parent Support Groups and Programs

SECTION I: Organizing and Developing Parent Support Groups and Programs

Anglin, J.P. (1985). Developing education and support groups for parents of children in residential care. *Residential Group Care and Treatment*, 3(2), 15-27.

"Family support is both one of the best predictors of a child's success in residential treatment and the most important single factor in determining the child's postdischarge adaptation. The author presents a systematic framework for staff in residential programs who may wish to develop parent groups as a means to enhance family support for children in care". (article abstract)

Parent groups can enhance residential care throughout the child's treatment process. Group support can begin at intake and continues as a follow-up service after the child leaves residential care.

Mutual help, sharing information, skill building, skills developing informal support networks, and offering opportunities for emotional release and support are considered to be significant characteristics of these parent groups. The author distinguishes between the different types of leadership required by parent groups and provides prospective group leaders (parents or professionals) with guidelines for typical group processes and content. The article also addresses some basic assumptions professional group leaders should use when working with parents in a learning environment.

Brownstone, D. (1989). *Parents together: A manual for leaders of support groups for parents of children experiencing emotional and behavioral disorders.* Albany, NY: Ulster County Mental Health Association. (Copies may be obtained from: Production Services Unit, New York State Office of Mental Health, 44 Holland Avenue, Albany, NY 12229).

This comprehensive manual provides information about organizing, facilitating, and maintaining support groups for parents of children affected by serious emotional and behavioral disabilities. The materials in the manual are oriented toward parent and professional leaders of these support groups. Some of the factors which should be considered when starting a new group include: assessing the parents' needs; identifying the components of a successful group, such as the size of the group, frequency and duration of meetings, publicity, child care and transportation; and, determining group goals. Samples of a newspaper advertisement, brochure, press release, and flier are illustrated.

Practical suggestions are given for handling group dynamics and parents' questions about the disabilities which their children experience.

The majority of the manual (77 out of 118 pages) is devoted to ideas for meeting topics. These topics include imprinting, issues regarding loss and grief, and parenting skills such as reflective listening, using "I" statements, dealing with children's

emotions, discipline, and behavior management. The author provides outlines for 38 exercises group leaders can use with parents.

The manual includes information about organizations engaged in advocacy activities in New York and other states on behalf of families of children with serious emotional disabilities. A list of suggested resources and written publications is provided at the end of the manual.

Des Jardins, C., Goetz, B., Levin, R., Handley, D., Ayres, E., Cotter, M., Teplitz, B., Brown, B., Sullivan, J., Pfrommer, M.C., and Rice, B. (1980). *How to organize an effective parent/advocacy group and move bureaucracies.* Chicago, IL: Coordinating Council for Handicapped Children (220 S. State, Chicago, Illinois 60604, (312)939-3513).

The primary theme in this handbook is empowerment of parents of children with disabilities. The authors present a strong argument for parents being the most competent and effective leaders, organizers, and advocates for children with disabilities. An activist approach is proposed for creating, organizing, and implementing advocacy-oriented parent groups, coalitions, and specialized school programs. Information is also provided about enhancing group longevity and vitality.

The authors also give advice about the use of lawyers and the mass media, lobbying, financial matters, and ways of distinguishing between "bureaucrats" and "public servants" and working with these professionals. Several approaches for community organization and public administration are discussed in detail.

Dickman, I.R., & Gordon, S. (1985). *One miracle at a time: How to get help for your disabled child--from the experience of other parents.* New York, NY: Simon and Schuster.

This book offers valuable information regarding ways in which parents of children with a disability may obtain assistance from physicians, therapists, and other parents. Information is also provided about financial aid, advocacy, and education for parents and their children. The authors also offer tips on negotiating the legal, medical, educational, and social service systems.

The notion of parental mutual support as a major part of family survival is discussed throughout the book. Parents may be particularly interested in chapters 4 and 5, which specifically address the value and benefits of parent support groups and include suggestions for locating existing support groups and for starting new groups. Appendices include lists of agencies serving individuals with disabilities and self-help clearinghouses.

Donner, R., & Fine, G.Z. (1987). *A guide for developing self-help advocacy groups for parents of children with serious emotional problems.* Washington, D.C.: Georgetown University Child Development Center (3800 Reservoir Road, N.W., Washington, D.C. 20007).

The primary objective of this workbook is to assist parents and professionals in developing self-help/advocacy groups for parents of children with serious emotional disabilities. The authors refer to self-help as based on a trusting, supportive environment to allow a group of individuals to come together to help themselves and each other with a common need or problem.

Frequently, advocacy evolves from the self-help environment, enabling parents to initiate positive changes in the quantity and quality of services, policies, and systems affecting their children.

The workbook is a product of the authors' knowledge and personal/professional experiences and is designed to help those developing groups achieve several tasks: (1) create a start-up plan for group development; (2) establish effective methods for accessing parents; (3) prepare several options for eliminating or overcoming obstacles to group development; (4) become acquainted with the names and demeanors of community agencies and professionals serving children with serious emotional disabilities; (5) develop an outline for the content and format of the first parent meeting; and (6) assess potential group directions and activities within three months after start-up. The authors emphasize the use of their workbook as a general guide for organizing parent self-help/advocacy groups, rather than as a prescribed plan of action. They also encourage individuals initiating groups to assess the needs of parents in their communities thoroughly and to remain receptive to change.

Fox, M. (1987). Anatomy of a parents' organization: The story of VOICE for Hearing Impaired Children. *Volta Review*, 89(5), 111-118.

The author describes the history and structural evolution of VOICE for Hearing-Impaired Children (VOICE) in Toronto, Ontario, which is noted as the largest parent support group of its kind in North America. In the 1960's, the organization's projects were oriented toward information sharing and providing educational programs and parent support groups. In recent years, their province-wide expansion has led to the creation of chapters and parent groups, advocacy in social and educational policy, and implementation of various service delivery models. VOICE has been instrumental in influencing legislation affecting children with hearing impairments.

The auditory-verbal model requires parents to be the primary managers of their children's linguistic, social, and educational development. VOICE parents have historically been committed to keeping their children at home (as opposed to provincial residential centers) so that they can be educated in local schools, enjoying normal childhood and family experiences. The organization is characterized by its responsiveness to parents' needs and effective work with professionals and other agencies/organizations in the service delivery system.

The author provides suggestions for parents who wish to start a support group, particularly the need for flexibility to accommodate the group's structural needs and goals, maintain continuous developmental activity, use various problem-solving techniques, and give attention to community needs. (Edited abstract)

Hoppe, P. (1979). How to organize self-help groups in the schools. *Exceptional Parent*, 9(4), 22-23.

The author presents several suggestions for overcoming specific difficulties in organizing parent self-help groups in the school system. These difficulties include: ways of expanding the group beyond the initial two or three interested parents, sources and methods of obtaining information regarding the rights of children with disabilities, the process of developing a list of group goals, effective techniques in meeting with school personnel, and strategies for monitoring commitments made by school staff and for sustaining the group. Pragmatic suggestions include: sending a note home with each child in the special education class regarding the first self-help group meeting; contacting local and state politicians; determining children's greatest needs and the gaps in the service delivery system; providing a copy of the group's priorities to each group member, school board member, and local, state, and federal government representative; meeting with the school board; recording names and commitments in writing; and, holding school officials accountable for their commitments. The author stresses that parents are the most important advocates in their children's lives and the use of mutual aid as an effective way of getting the needed information.

Hornby, G. (1988). Launching Parent to Parent schemes. *British Journal of Special Education*, 15(2), 77-78.

This article is written for those interested in developing a Parent to Parent program which is a telephone self-help service for parents of children with special needs. The helpline is staffed by a team of volunteers who are also parents of children with disabilities and have been recruited and trained by professionals. Potential volunteer parents are recruited through contacts with existing parent organizations. Interested parents are invited to an informational meeting to learn about the program and the guidelines for volunteer participation. Each 8-week training session is limited to fourteen parents who have children with different types of disabilities. Various techniques are utilized to teach parents about effective listening skills, assisting callers in understanding the problem, and action planning. After completing the training, parent volunteers typically assist with the program's administrative tasks, such as finances, publicity, community or professional liaison or training.

Parents learn of the helpline through leaflets, posters, or cards in locations frequented by parents (schools, libraries, health services). The author recommends that professionals interested in developing this service use the Parent to Parent training manual for comprehensive guidelines in training volunteers.

Nathanson, M.N. (1986). *Organizing and maintaining support groups for parents of children with chronic illness and handicapping conditions.* Washington, D.C.: Association for the Care of Children's Health (3615 Wisconsin Ave., N.W., Washington, D.C. 20016, (202)244-1801).

This handbook provides numerous resources for parents and professionals involved in ongoing support groups, newly forming groups, or interested in starting their own parent support groups. The handbook focuses primarily on groups for parents of children with chronic, life-threatening, and handicapping conditions, and provides detailed and practical information necessary to start and maintain support groups.

Readers will find this information helpful in making decisions about group philosophy, goals, activities, membership composition, leadership, referral, and funding. Guidelines are given for forming an affiliation with a larger organization and for creating a state, provincial, or national organization.

The author also discusses methods of forming coalitions and networks with groups with similar concerns and interests and group maintenance issues, such as conflict, burnout, and longevity.

The handbook also provides sample documents such as letters, questionnaires, brochures and fliers, bylaws, public service announcements, and handouts.

Pizzo, P. (1983). *Parent to parent: Working together for ourselves and our children.* Boston, MA: Beacon Press.

This book is designed to provide an overview of the dimensions of self-help and advocacy among parents. The author limits her focus to parent groups involved in self-help and advocacy, with descriptions of activities of more than fifteen parent organizations and of the historical and social forces influencing these organizations. The groups were all developed and directed by parents.

Most of data contained in the book were obtained from the author's interviews and contacts with members of local, state, and national parent organizations. Information and suggestions are provided regarding organizing parent groups, advocacy, locating and starting groups, and the factors influencing their success and failure. In influencing professional and public opinion and educating professionals, academicians and researchers will find important information about the relationships between parents, government, institutions, and professionals. The author argues that it is critical for professionals to understand and utilize parents as resources. Child and family advocates will find pragmatic, successful strategies and resources to assist them in alleviating the social conditions harmful to children. Parents' perspectives on policies and programs effective in meeting children's needs will be of interest to administrators and policy makers. Of particular interest are the services provided by parent groups for their members, the factors motivating parents to become involved in institutional reform, effective reform strategies, and the common needs, problems, and practices of parent groups. As a parent and helping professional, the author provides an excellent resource for those seeking to improve services for children.

Reynolds, K., & Shanahan, V. (1981). *The Parent to Parent Program organizational handbook.* Athens, GA: University of Georgia, University Affiliated Facility, Parent to Parent National (850 College Station Road, Athens, Georgia 30610-2399, (404)542-6629, 542-8790).

"This handbook is a compilation of ideas, letters, forms, agendas and other material developed for the Georgia Parent to Parent Program during its first two years of operation (Fall 1981-1983) to facilitate the establishment of local Parent to Parent Programs" (p. 1). The handbook provides detailed step-by-step information for parents of children with developmental disabilities and professionals interested in starting a new Parent to Parent Program. Although some materials are specific to Georgia's social service delivery systems and to parents of children with developmental disabilities, general ideas for the Program's creation, organization, and implementation could be adapted to address the needs of parents of children with other types of disabilities. An extensive outline is provided with suggestions for creating a statewide Parent to Parent organization.

Shelton, T.L., Jeppson, E.S., & Johnson, B.H. (1987). *Family-centered care for children with special health care needs.* Washington, D.C.: Association for the Care of Children's Health (3615 Wisconsin Ave, N.W., Washington, D.C. 20016, (202)244-1801).

"Not only is the family the primary unit for the delivery of health services to infants and children, but the family environment is probably the greatest influence upon a child's health . . . The family is . . . also the intermediary between the child and the outside world, including the health care system . . ." (p. 1).

The preceding quotation reflects the family-centered philosophy of care advocated by the health care system to address children's needs in the health care system. A model for a family-centered approach is presented which consists of eight different components. The authors define and analyze each component, present examples of existing family-centered programs/policies, and utilize a systemic framework in examining each component.

One of the key elements of a family-centered approach to care is mutual support among parents. The authors discuss three functions of parent support, structure and organization of parent support groups, and strategies for developing parent mutual support. The parameters of family-centered care are clarified in excerpts from parents of children with chronic illnesses or disabilities and from professionals who work with these families. This approach could be particularly useful to advocacy-oriented parent groups involved in planning, implementing, and monitoring programs and policies for children with disabilities.

Straw, P. (1982). *Awakenings: Organizing a support/advocacy group.* Washington, D.C.: The National Alliance for the Mentally Ill (1200 15th Street, N.W., Suite 400, Washington, D.C. 20005).

Focusing specifically on the National Alliance for the Mentally Ill, the author provides a brief history and description of support/advocacy groups and emphasizes the reasons that these groups are needed.

Guidelines are provided for starting new groups and for effecting positive change in the mental health system. Since families participating in self-help groups have different levels of need, groups must be able to address the needs of all families at least partially during each meeting. The author's framework for describing three primary categories of need would be quite helpful to facilitators and members of parent support groups. In addition, several of the appendices could assist parent support groups with development and maintenance issues.

Wilkerson, S.E. (1985). *Connect with parents: Build support groups.* Conference proceedings, conference sponsored by the Administration for Children, Youth, and Families (DHHS), Washington, D.C. (Available from Colorado Department of Social Services, Division of Family and Children's Services, 717 17th St., P.O. Box 181000, Denver, CO 80218-0899).

This [handbook] is a guide for the establishment and maintenance of parent support groups. It is a result of a conference on building parent support groups sponsored by the Colorado State Department of Social Services which brought together professionals and parents. The suggested audiences are people interested in forming similar groups; non-profit agencies interested in structure, financing, and marketing; and existing formal and informal support groups. The [handbook] consists of thirteen articles on relevant topics. Fund raising, marketing, and choosing board members are discussed in the first section. Advice on getting it off to a good start with support groups, stories of successful groups, and the use of para-professionals are included in the second section. Special interest groups including Parents Anonymous, mothers' support groups, and single parent groups are also discussed. Many articles include bibliographies. An appendix gives national and state resources for program development in child abuse/neglect prevention. (ERIC document resume abstract)

SECTION II: Organizing and Developing Self-Help Groups and Organizations

SECTION II: Organizing and Developing Self-Help Groups and Organizations

Johnson, J.T. (1988). Starting your own self-help group. In J.T. Johnson, *Hidden victims: An eight-stage healing process for families and friends of the mentally ill* (pp. 164-176). New York, NY: Doubleday.

A chapter on starting self-help groups explains that the purpose is to promote healthy, positive coping behavior. The author offers ideas for publicizing the group, obtaining a meeting place, deciding upon the group's purpose and style of leadership, facilitating and meeting with the group. A sample outline and guidelines for meetings are presented. Information is provided about the prerequisite characteristics of group facilitators and their roles. Most of the suggestions are designed for those interested in forming support groups for family members of people with mental disabilities.

Lakey, B. (No date). *Meeting facilitation: The no magic method.* Philadelphia, PA: New Society Publishers (4722 Baltimore Ave., Philadelphia, PA 19143).

This booklet provides clear and concrete suggestions for working with groups. The author makes a clear distinction between a group leader and facilitator, with the latter assisting the group in achieving a common goal and refraining from controlling or making decisions for the group. Suggestions are given for group pre-planning, developing agendas, facilitating meetings, managing conflict and building consensus, observing and discussing group process issues, and providing closure.

Lemberg, R. (1984). Ten ways for a self-help group to fail. *American Journal of Orthopsychiatry*, 54(4), 648-650.

The author describes the importance of self-help groups as a competence-enhancing community resource, with the reservation that many groups are destined for failure due to their organizers' inexperience or lack of commitment. The author warns that self-help groups can foster individual dependence upon the group, promote authoritarian belief systems, and allow an antiprofessional stance to prevent useful collaboration with professionals.

Ten reasons for group failure are presented: failure to create group cohesion; attracting/recruiting the most "dysfunctional" individuals possible; preventing emergence of strong leaders; failing to rotate leadership; allowing members to remain passive and avoid interaction; allowing communication to occur only between the leader and individual group members; promoting active, superficial (chaotic) communication; failing to require members to assume responsibility for group functioning and maintenance; failing to meet the needs of the group leaders; and refraining from personal involvement or risk-taking. (Edited abstract) Although this article specifies potential failings of self-help groups, the author's intent is unclear.

*Lieberman, M.A., Borman, L.D., & Associates (1979). *Self-help groups for coping with crisis: Origins, members, processes, and impact.* San Francisco, CA: Jossey-Bass Publishers.

This book is the collaborative effort of several researchers and mutual-aid groups. Initial research findings and the consequent development of theory provide insight into important aspects of self-help groups: their origins, organization, and development; the types and circumstances under which issues are addressed; the factors influencing group effectiveness; the ways in which self-help groups function; and, the factors influencing group longevity. The authors focus primarily on groups attempting to induce change in participants' behavior or attitudes (i.e., Alcoholics Anonymous, Parents Anonymous, TOPS, Recovery, Inc.) and groups that assist participants in adapting to major life changes or catastrophic conditions (i.e., Compassionate Friends, Mended Hearts, Widow-to-Widow).

The book is organized in four parts. Part One (How Groups are Started and Structured) examines case histories of the following self-help groups from an organizational development perspective: Mended Hearts, Compassionate Friends, Naim, and women's consciousness-raising groups. Part Two (Who Participates in Self-Help Groups) discusses the purposes and goals of member participation, the ways in which individuals gain access to self-help groups, and the ways in which the quality of one's social network influences motivation to join a group. The four chapters in Part Three (How Self-Help Groups Work) provide information about the nature of help received by group members. Specifically, this section explores the role of group ideology as a "cognitive antidote" for the shared group "affliction" and the particular mutual experiences and interactions occurring during group meetings. Outcome evaluation of participation in various self-help groups is the focus of Part Four (Evaluating the Impact of Self-Help Groups). Questions of measurement, study design, and policy implications are explored.

Lyon, E. (1988). Self-help groups: An agency's experience. *Social Casework*, 69(8), 525-529.

A private, non-profit social service agency's experiences with two self-help groups are described. The groups evolved from the agency's Family Life Enrichment program; one group is for individuals who are separated or divorced and the other group involves young widows and widowers. Characteristics of group members, group process, outcomes, and planning issues are discussed.

The author makes three recommendations for professionals who wish to initiate self-help groups for clients experiencing similar difficulties: (1) clarify the group leadership model and role of the professional(s) from the beginning; (2) structure activities to enhance group commitment; and (3) screen potential members carefully to obtain a specialized group composition. These are important recommendations because of their influence on the degree of satisfaction members experience from group participation.

Madara, E.J., & Meese, A. (Eds.). (1986). *The self-help sourcebook: Finding and forming mutual aid self-help groups.* Denville, NJ: Self-Help Clearinghouse. (St. Clares Riverside Medical Center, Denville, NJ 07834, (201) 625-7101).

This resource book provides consumers, professionals, and students with comprehensive and valuable information about self-help groups and organizations throughout the United States. Numerous listings are included: a national directory of self-help groups and organizations; a national listing of self-help clearinghouses; over 400 problem- or situation-specific self-help resources (i.e., for addictions, parenting issues, mental health, illnesses or disabilities); a list of resources for rare disorders; toll-free helplines; suggestions of ways to use the resource book; and, a well-organized index for easy access to all listed resources.

In the book's introduction, self-help groups are defined and their differences compared according to structure, activities, and the nature of help provided. Reference is also made to the nature of relationships between professionals and self-help groups and their potential for becoming adversarial or collaborative. Five guidelines are provided for those interested in developing a self-help group: (1) "Don't re-invent the wheel"; (2) "Think mutual-help from the start"; (3) "Find a suitable meeting place and time"; (4) "Publicizing and running your first public meeting"; (5) "Future meetings". Directly following this section is a discussion of the importance of professionals' roles as consultants to self-help groups. The author provides an overview of ten basic steps professionals can take in assisting in developing self-help groups.

*Medvene, L.J. (1985). An organizational theory of self-help groups. *Social Policy*, 15(3), 35-37.

The author spent fifteen months interviewing leaders of various self-help groups. The exploratory nature of the interviews revealed a potential connection between organizational theory and a particular aspect of the structure of self-help groups. The author refers to this structural component as the infrastructure of helping roles. Self-help groups vary extensively in their organization and methods of achieving goals. The infrastructure can promote or hinder the process of mutual aid, support, and sharing between group members as well as experiential learning and the helper-therapy principle. The infrastructure of helping roles is related to a group's effectiveness and ability to accomplish goals; this structure exists independently of formal leadership or officer roles. The author presents examples of explicit, extensive infrastructures, such as the Alcoholics Anonymous system of sponsorship, Recovery, Inc.'s presenter-respondent pattern of member interaction, and the role of discussion group leader in both organizations. These infrastructures are compared to less formal group structures.

*Rappaport, J., Seidman, E., Toro, P.A., McFadden, L.S., Reischl, T.M., Roberts, L.J., Salem, D.A., Stein, C.H., & Zimmerman, M.A. (1985). Collaborative research with a mutual help organization. *Social Policy*, 15(3), 12-24.

An extensive history is presented regarding the authors' evaluation of the need for ongoing, community-based alternatives for people with long-term mental disabilities. The authors assert that helping alternatives must create for beneficiaries a sense of empowerment, rather than dependency. Mutual help within a person's natural environment is considered by the authors to be one of the most viable helping alternatives. Mutual help organizations significantly expand the choices available to people with difficulties in day-to-day life.

The authors present the history of their collaboration with the founder of Grow International, a mutual-help organization for people with long-term mental disabilities. A description is presented of a longitudinal study (still in process) which evaluates individual participants, group process, and the development of the organization. The article offers preliminary findings and addresses the present and potential roles of mental health professionals in helping or hindering of organizational expansion.

Weber, G.H., & Cohen, L.M. (Eds.). (1982). *Beliefs and self-help: Cross-cultural perspectives and approaches.* New York, NY: Human Sciences Press, Inc.

The phenomenon of self-help evolves through numerous forces in society, which may be spontaneous or the result of cultural traditions, beliefs, and values. Specifically, forces that stimulate the process of self-help include: a state of social discontent (individual or group); inadequate or nonexistent social structures to remedy social discontent; contact between discontented individuals or groups; mutual agreement among the discontented that past or current social structures have failed to meet their needs; shared beliefs and expectations that mutual aid and planned actions will improve their circumstances; and, a shared ideology which justifies and supports their planned efforts.

Once self-help groups evolve, they assume different degrees of organization. The editors use a continuum framework to examine unique group characteristics and functions. "Well organized groups" exhibit a high degree of cohesiveness and loyalty among members and group ideologies tend to regulate their behavior. Ethnic groups often fall into this category. At the other end of the continuum are "fledgling groups", whose members do not always express shared norms or beliefs. These groups typically exhibit low cohesion and stability.

This book is a collection of eight papers which reflect varying degrees of group organization, ethnicity, socialization, beliefs, structures, functions, and dynamics. Ethnicity, beliefs, culture, and cross-cultural issues are common themes in each paper. The book concludes by giving attention to the enormous influence of belief systems on self-help groups and to the papers' contributions to our knowledge about the development and functioning of these groups. (Edited prologue, pp. 27-29)

SECTION III: Professionals' Roles in Parent Support Groups and Programs

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Klass, D., & Shinners, B. (1982). Professional roles in a self-help group for the bereaved. *Omega: The Journal of Death and Dying*, 13(4), 361-375.

Self-help groups are a relatively new and useful aid to the bereaved. The movement creates a sense of community, puts the locus of control on the individual, and emphasizes interaction and growth. Some of the literature regarding self-help groups raises the question of the role of professionals, since such groups may be indifferent or occasionally resistant to professional intervention.

This paper grew out of [the authors'] experience with a local chapter of the Compassionate Friends [TCF], a group of bereaved parents. It is an attempt to show how professionals can work within the self-help movement despite the gap between self-help and professional ideologies. [The authors] have sketched five areas in [their] roles as professionals which seem to have proven useful to [their] TCF chapter: 1) intermediary between the group and the professional community; 2) articulating the group's ideology to the group itself; 3) resource person in program planning; 4) facilitator of group processes and organization; and, 5) research. This paper also explores the topic of referral to professionals for parents in acute grief, manifested by behavior that resembles psychosis. (Edited abstract)

Lowenstein, A., Watson, A., del Valle, P., Branciforte, R., Pugh, A., Fernandez, R., & Pope, C. (1981). *Parent support group training manual. TOPS Program: A school/mental health cooperative.* Miami, FL: Dade County Public Schools. Sponsored by the Office of Special Education and Rehabilitative Services (ED), Washington, D.C. Division of Innovation and Development.

This is the second of two reports regarding the TOPS Program (Teaching Outreach Prevention School), which is a group work approach for elementary students with emotional disabilities. This report describes TOPS' parent groups. These groups are focused primarily on parent training, but also contain an element of parent-to-parent support. The needs and purposes of parent groups are discussed, particularly for parents of children with emotional disabilities. Techniques for motivating parents are noted, including providing opportunities for sharing information and suggestions. The thrust of the approach is to allow parents to understand their child's behavior patterns and to help them handle problems. Objectives and goals of parent training are presented with an agenda for six sessions, which focus on discipline, behavior management, and assertiveness training. Appended is a paper by S. Berkowitz, "ABC's of Behavior Modification." (Edited ERIC document resume abstract)

Moore, J.B. (1983). The experience of sponsoring a Parents Anonymous group. *Social Casework*, December, 585-592.

The author asserts that sponsoring a Parents Anonymous group can provide social workers with a strong sense of gratification as group members typically show significant growth and change within a fairly brief time period. In contrast to a typical clinical role, a sponsor engages in a peerlike, nondirective relationship with group members to promote trust and positive interaction. The most critical function of the sponsor is to offer a support system to group members and assisting the chairpersons in acquiring skills necessary for effective leadership. The sponsor may also coordinate publicity and should provide transportation to meetings as needed by group members. The author stresses the importance of the group sponsor maintaining a supportive, advisory position, refraining from addressing group members as clients. The author also discusses ways to avoid burnout, the dilemma of confidentiality and child abuse reporting requirements for professionals, and ways to balance the dual role of sponsor and group member.

Vosler-Hunter, R., & Exo, K. (1987). *Working together: A training handbook for parent-professional collaboration.* Portland, OR: Portland State University, Research and Training Center to Improve Services for Seriously Emotionally Handicapped Children and Their Families, Regional Research Institute for Human Services (P.O. Box 751, Portland, OR 97207, (503)464-4040).

When professionals and parents of children with severe emotional disabilities work together, a comprehensive, effective, and meaningful network of support and services can be created for children and their families. Parent-professional collaboration enables families to locate and request available appropriate services for children with emotional disabilities. Collaboration can provide the impetus for parents to form support groups and for advocacy in creating new services and positive changes in larger systems. This handbook is designed to assist parents and professionals in overcoming potential barriers to collaboration; it may also be used as a training guide for agencies, groups, or individuals interested in developing parent-professional collaboration in the community. Various handouts, lists of definitions and rights, suggestions for parent/professional roles, and information about parent support groups will be helpful in addressing issues related to the start-up and maintenance of such groups.

Willen, M.L. (1984). Parents Anonymous: The professional's role as sponsor. In A. Gartner & F. Reissman (Eds.). *The self-help revolution* (pp. 109-119). New York, NY: Human Sciences Press, Inc.

The author describes her personal experience as a professional sponsor of a Parents Anonymous group. She discusses the nature and function of the sponsorship role as distinct from that of group leader and the critical need for support and back-up from the sponsor's agency. A description of the operational details of group sponsorship is provided. Issues such as confidentiality, publicity, recruitment, and ethical dilemmas are addressed. Some of the parents' experiences are incorporated into the author's framework for sponsoring a Parents Anonymous group.

SECTION IV: Professionals' Roles in Self-Help Groups and Organizations

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Auslander, B.A., & Auslander, G.K. (1988). Self-help groups and the family service agency. *Social Casework*, 69(2), 74-80.

People join self-help groups for numerous of reasons, including assistance in coping with difficult or unexpected life transitions, failure of professional services to meet people's needs, and a lack of trust in the efficacy or intentions of professionals' interventions. Others utilize self-help groups to avoid the stigma attached to seeking help or to supplement other services they are receiving. Social workers are frequently uncertain about how to interact with self-help groups. Some authors describe workers as resistant and antagonistic toward these groups, whereas other studies have found workers to view self-help groups quite positively.

The authors contend that the social service agency, although typically absent from the equation, could be a policy and programmatic link between self-help groups and the social work profession. A description is provided of a self-help group consultation program that was developed, implemented, and evaluated by a family service agency. A self-help coordinator provided technical assistance to existing groups and to those interested in forming new groups; the coordinator also acted as a referring and linking agent between groups and concrete services (physical facilities, financial resources, other agencies/providers) and developed new groups in areas where the need existed. The family service agency benefited from this involvement through increased public visibility, referrals, and applications for service. In addition, the community could provide a wider range of services, resulting in increased opportunities to assist previously underserved populations. The authors also discuss some of the problematic issues between the agency and self-help groups.

Chutis, L. (1983). Special roles of mental health professionals in self-help group development. In R. Hess & J. Hermalin (Eds.), *Innovations in prevention* (pp. 65-73). New York, NY: The Haworth Press, Inc.

Provision of services to self-help/mutual aid groups is a natural outgrowth of the goals, objectives and activities of consultation and education (C & E) departments of community mental health centers. The C & E services of the Ravenswood Community Mental Health Center has, during the past several years, provided numerous forms of assistance to a variety of self-help groups in the Chicago area. Through this experience, the roles of mental health professionals in facilitating the development and maintenance of self-help groups have been explored. Four primary areas involved in group development include: establishing agency priorities and commitments in working with self-help groups; establishing a core staff group and possible group participants to work on group facilitation; formalizing the group; and re-evaluating the ongoing need for staff involvement. The provision of assistance without challenging the autonomy and voluntary nature of self-help groups is a basic requirement for all professionals involved in group development. With careful recognition of the needs and nature of such groups, mutually satisfactory long-term relationships can be established between self-help groups and mental health professionals. (Edited abstract)

Madara, E.J. (1987). Supporting self-help: A clearinghouse perspective. *Social Policy*, 18(2), 28-29.

"Self help clearinghouses represent one of the most exciting and innovative forms of human service today. Over 40 self-help centers have been created across the country over the last decade, each of which has been finding new and different ways to increase the awareness, use, and development of self-help groups in their communities. These clearinghouses also serve as bridges for increasing communication and collaboration between the self-help and professional communities. Clearinghouses demonstrate, through their work, some of the possibilities that exist for any organization to promote and collaborate with self-help groups in better meeting people's health and human needs" (p. 28).

In addition to discussing the functions and future potential of self-help clearinghouses, the author gives a brief history of the development of the New Jersey Self-Help Clearinghouse. He also stresses the importance of positive relationships between professionals and self-help groups; a healthy sense of equality and mutual respect is essential for an effective partnership to occur. The author believes that the most appropriate role for a professional to assume is that of a consultant, offering advice and assistance to self-help groups based on professional knowledge.

Platman, S.R. (1982). The chronically mentally ill: Sharing the burden with the community. In D.E. Biegel & A.J. Naparstek, (Eds.), *Community support systems and mental health: Practice, policy, and research* (pp. 190-201). New York, NY: Springer Publishing Company.

This chapter concludes Part II (Programmatic Interventions) with a discussion of support systems for people with chronic mental disabilities. The author documents both the severe problems facing this population group and the strong stigma felt toward them by the general public. Deinstitutionalization problems of the 1960s and 1970s are well known and the author discusses a number of "innovative" model programs that were developed just prior to the time this article was written. While he believes that these programs have achieved some successes, they are primarily dominated by service providers and tend to increase the dependency of people with chronic mental disabilities and provide little support to their families. Professionals are urged to encourage and participate in the development of self-help programs for people with chronic mental disabilities; the author cites the positive experiences of both Fountain House and the Fairweather Lodge models (in New York state) in which professionals held major roles in the program development. He warns that self-help groups should not be anti-professional, but should utilize professional assistance when appropriate and helpful. (Edited abstract)

Silverman, P.R. (1980). *Mutual help groups: Organization and development.* Beverly Hills, CA: SAGE Publications, Inc.

This book is written for human service professionals interested in organizing a mutual help group. Professionals often have clients experiencing similar difficulties who could benefit from a mutual help group. However, many professionals lack information, training, or experience with regard to mutual help groups, thus making it quite difficult for them to initiate such groups. The author provides detailed, pragmatic information to assist professionals in identifying clients who could benefit from participating in a mutual help group, deciding the type of group that would be most appropriate in addressing clients' needs, and organizing and initiating a group.

"There are ten chapters in the book. The first consists of a general description of mutual help and mutual help groups so that there can be some common understanding of and agreement on the meaning of the terms. The second chapter discusses professional attitudes which may either impede or enhance the successful achievement of [group] goals. The next four chapters present materials which should help [the professional] to identify [the] target population, determine what kind of group [is best] to develop, and take the steps required to organize it. The final three chapters are devoted to the ways and means by which groups can be maintained over time" (p. 8).

Silverman, P.R. (1982). The mental health consultant as a linking agent. In D.E. Biegel & A.J. Naparstek (Eds.), *Community support systems and mental health: Practice, policy, and research* (pp. 238-249). New York, NY: Springer Publishing Company.

Part III (Professional Roles) concludes with a chapter which discusses the mental health professional's role as consultant to a mutual-help organization. The author presents a consultation model to enhance the capability of mental health professionals to work with mutual-help organizations. She notes that relationships between self-help groups and professionals have been filled with considerable tension and conflict. Mental health professionals frequently have difficulty consulting with these groups. This may occur because the knowledge and experience bases of professionals are more suitable to "clinical" interventions with clients and in consultation with agency staff. In addition, professionals may not have empathetic attitudes toward mutual-help organizations, tending to judge the help given as superficial and increasing members' dependency. It is recommended that the mental health consultant act as a linking agent between mutual-help groups, helping them to share and exchange their expertise and knowledge. Facilitating a mutual learning process is an appropriate model of consultation, since mutual-help groups are fluid organizations with very diverse structures and ideologies.

Wilson, P. (1983). Towards more effective intervention in natural helping networks. *Social Work in Health Care*, 9(2), 81-88.

Although the use of social networks is discussed in the research literature, the author asserts that professional approaches to intervention rarely utilize available research findings. One of the primary intervention approaches discussed in the literature is the formation of artificial networks (i.e., self-help groups). The author discusses four areas that need to be considered when researching self-help groups: evaluating the responses of a client's social network (i.e., family, friends) to their decision to join a self-help group; identifying leaders within a client's social network and their roles; using network characteristics to create instruments to assess network resources; and, examining changes in networks over time.

*Wintersteen, R.T., & Young, L. (1988). Effective professional collaboration with family support groups. *Psychosocial Rehabilitation Journal*, 12(1), 19-31.

This article describes a study of the educational process involved in support groups for families of individuals with a mental illness. The study involved members of the support group of Kansas Families for Mental Health, who were requested to comment on the roles, actions, and attitudes of professionals involved with their group. Study observations and information from other sources are utilized to develop a set of self-help practice principles for professionals.

Findings showed that group members were highly satisfied with leadership and morale; members felt competent and acted effectively to further their goals and articulate their needs with professionals and community agencies; and, the group focus tended to evolve over time from individual and family concerns to more advocacy-oriented activities.

More than two-thirds of study participants were members of groups in which professionals acted as advisors or liaisons. Nearly all respondents (96%) indicated that a professional advisor proved helpful to group functioning and individual education, as long as the professional maintained a very limited role. Based on these findings, the authors provide ten suggestions for professional practice with self-help groups. The guidelines for professionals include helping family support groups to organize, recruit members, and become better known in the community. Professionals are urged to assume roles as enablers, educators, and catalysts committed to reciprocal learning, rather than being the sole leaders or quasi-therapists of family support groups.

SECTION V: Benefits and Descriptions of Participation in Parent Support Groups and Programs

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*Galanter, M., Gleaton, T., Marcus, C.E., & McMillen, J. (1984). Self-help groups for parents of young drug and alcohol abusers. *American Journal of Psychiatry*, 141(7), 889-891.

A study was conducted of parent self-help groups addressing child and adolescent drug abuse; one of the purposes of the study was to educate and assist psychiatrists in working with these groups. The authors studied a sample (135) of parent group members who attended a conference sponsored by the Parent Resources Institute for Drug Education (PRIDE). Parents answered questions regarding their children's drug and behavior problems, demographic characteristics, and their group's structure, focus, cohesiveness, and shared attitudes and the perceived benefits of group participation. Although groups were quite similar with regard to a distinctive shared ideology and high degree of social cohesiveness, their structure and activities varied widely. In addition to parents' reports of improvements in their children's drug and behavior problems, the authors suggest that group participation may help parents cope better with their children's problems. The authors recommend that subsequent studies be conducted at the community level and that subjects be asked for prospective, rather than retrospective observations. Psychiatrists are urged to provide diagnostic assistance and consultation and to exercise flexibility when working with parent self-help groups.

*Kagey, J.R., Vivace, J., & Lutz, W. (1981). Mental health primary prevention: The role of parent mutual support groups. *American Journal of Public Health*, 71(2), 166-167.

An evaluation is presented of a community mental health center's support group program for parents of newborns. The program was considered to be primary prevention because groups began prior to the onset of any problems. Parents participated in groups of five to eight with a two-session coffee format, beginning three weeks after delivery. Mutual support groups were facilitated by parent volunteers and group content was determined by participating members.

Responses to 98 mailed surveys indicated that groups were instrumental in providing parents with helpful social contact and enhanced positive feelings about their parental roles. Although group support increased parents' understanding of child development and of their child-caring skills, group participation apparently did not improve relationships between spouses.

*Klass, D. (1984). Bereaved parents and the Compassionate Friends: Affiliation and healing. *Omega: The Journal of Death and Dying*, 15(4), 353-373.

In this article, the author describes The Compassionate Friends (TCF) self-help group as an effective intervention in parental bereavement of the death of a child. The authors utilize participant observation as a means for analyzing and describing the TCF process the way in which parents move through that process. The descriptive framework has three components: the parent's decision to attend the group, affiliate with the group, and transition into a helper role within the group. The decision to attend the group seems to be rooted in a variety of expectations, supported by numerous experiences with professional interventions or with other self-help groups.

Affiliation requires a "cathectic" dimension involving social and emotional contact with other parents who have lost children or with an appropriate object, activity, or direction for focusing the energy formerly given to the child; a sense of family is needed within a supportive environment. In addition, affiliation has an experiential dimension that involves developing an existential stance in a problematic world, which is based on solutions to the problems group members share.

The decision to assume the helper role is key to the TCF process because helping others is considered the best way to help oneself. This role also gives parents a focus outside themselves, allowing them to reinvest in life through sharing. Candid excerpts from the author's interviews with bereaved parents illustrate various aspects of the grief process. As time progresses, some members assume to formal organizational leadership while others attend meetings less frequently, often with a degree of ambivalence. The author suggests that analyses of other interventions could utilize methods similar to those in this study. (Edited abstract)

Koehler, J. (1982). Mothers without children. *Children Today*, 11(2), 12-15.

Interviews with social service professionals and several non-custodial mothers reveal a wide range of factors leading to loss of child custody. The author distinguishes between mothers who have fought and lost custody battles and mothers who have chosen (passively or actively) to relinquish custody of their children to their ex-spouses. Women in both situations often experience pain, loss, and guilt, but those who actively chose to yield custody are often stigmatized as "bad" or "unhealthy" mothers and are socially devalued. Such difficulties can create isolation and role confusion and contribute to feelings of worthlessness. Sources of emotional support are crucial in assisting non-custodial mothers to cope effectively with their circumstances. The author founded Offspring, an organization for non-custodial parents in the Washington, D.C., area; the organization provides a referral service and support network. Monthly group meetings cover issues such as anger management, visitation, child support, and societal stigmatization of non-custodial mothers.

Kratochvil, M.S., & Devereux, S.A. (1988). Counseling needs of parents of handicapped children. *Social Casework*, September, 420-426.

The authors assert that parents of children with handicaps experience an extended, continuous grieving process that resembles chronic mourning; it may be unrealistic to expect parents to attain a sense of closure with their grief since they are confronted with their loss on a daily basis. The view that a parent's grief over the loss of an "ideal child" emerges in various forms at different points in the child's development is reflected in brief excerpts of the authors' interviews with parents. The authors assert that parents who experience periodic grief require support that will meet their specific needs at any given time. Four sources of support are discussed: spouses, family and friends, parent self-help groups, and professionals. The authors report parents' positive and negative opinions of the first three forms of support. Parents' attitudes regarding professional help are quite positive. The authors contend that self-help groups for parents are primarily to provide information and advice about service delivery systems and specific disabilities or handicaps. Some of the parents stated that their emotional needs have not been met by self-help groups. In addition, parents seem to experience decreasing benefits from these groups as their children grow older. Parents with older children also seem to receive less support from the service delivery system than parents of infants with disabilities or newly diagnosed children. The authors stress that utilizing the notion of periodic grief will assist professionals to respond effectively to the specific needs of all parents.

*Minde, K., Shosenberg, N., & Hines, B. (1978). *Self-help groups in a premature nursery: A controlled evaluation* (Report No. CG 013 175). Toronto, Ontario, Canada: The Hospital for Sick Children, Department of Psychiatry (ERIC Document Reproduction Service No. ED 165 077).

The researchers studied two groups of randomly chosen parents of premature infants during the first six months of their children's lives. The experimental group participated in a weekly parents' self-help group, which was staffed by a neonatal nurse and the parent of a premature child. The control group received routine medical services. Results of the study indicated that parents in the experimental group had more frequent contact (telephone calls and visits) with hospital staff and with their children than parents in the control group. Parents in the experimental group also reported feeling more comfortable with their caretaking role than those in the control group. Self-help group participants also had a higher incidence of parent-child physical contact and opportunities for sharing and intimacy; these parents also experienced greater self-esteem and fewer feelings of guilt than their control group counterparts.

Peach, M.R., & Klass, D. (1987). Special issues in the grief of parents of murdered children. *Death Studies*, 11, 81-88.

In this article, the authors describe their observations over a one-year period of a local chapter of the self-help group Parents of Murdered Children (POMC). The authors served as professional advisors to the group, providing consultation, friendship, and occasional group process facilitation. When a child is murdered, parents experience an especially difficult grief reaction which is complicated by four particular issues. Intense rage is focused on the murderers of their children and parents often have active thoughts and fantasies of revenge. It seems that their grief cannot be resolved until the necessary legal processes are completed. This is extremely troublesome if the criminal investigation and trials fail to lead to a conclusion or to a conclusion desirable to the surviving family members (i.e. lengthy incarceration of the murderer). In addition, the parents of a murdered child have no legal rights within the court system; parents in POMC are typically dissatisfied with the legal and criminal justice systems.

The third issue is that parents often fear for the safety of themselves and their family members. This fear is quite rational because the murderer is often a relative or someone known to the family and may not be incarcerated and continue to threaten survivors.

Finally, parents of murdered children are often socially isolated due to the taboo nature of their circumstances. These parents typically have to assume full responsibility for maintaining or reestablishing their social support networks. These special needs may not be met through participation in a group such as the Compassionate Friends; POMC was formed for this purpose. The self-help process of POMC groups differs from other groups for bereaved parents in addressing the extremely intense rage and drive for revenge; this is channeled into two types of action: parents assisting each other with continuous problems within the criminal justice system and in advocating for system reform.

Pearson, J.E., & Sternberg, A. (1986). A mutual-help project for families of handicapped children. *Journal of Counseling and Development*, 65, 213-215.

The authors describe an agency-sponsored program in Fairfax County, Virginia, which provides support and education for parents and siblings of children with disabilities. When the program was established in 1983, parent effectiveness training was provided; participants were then asked to start parent and sibling support groups. These groups eventually produced a video to be used by newly forming parent support groups regarding the resources and difficulties of living with a child with disabilities. The parent group currently sponsors free monthly presentations by staff of various community organizations serving people with disabilities. Topics are selected by parents and the lectures are open to the public. The parent support group is held once weekly for two hours. Groups are led by project volunteers trained in counseling and social work. Mutual support is facilitated through shared experiences, problems, information, and advice. Discussions are often focused on the service delivery system, school-related issues, dissatisfaction with professionals, financial problems, and personal issues. Group members also strive to increase community awareness of the needs of children with handicaps and their families through the use of local radio and television programs. Program volunteers lead a weekly sibling support group which coincides with the parent group.

Peterson, L.E., & Kelleher, C.C. (1987). Working with parents of disturbed adolescents: A multifaceted group approach. *Child Welfare*, LXVI(2), 139-148.

This article describes a parents' group model which is intended to complement family therapy provided by a Community Treatment Complex for adolescents with severe emotional disabilities. Eligibility for other treatment services is not contingent upon parents' participation in the group. The group is open-ended and is co-facilitated by two agency staff members and serves educational, therapeutic, and support functions. Parents are primarily in control of the frequency, duration, and content of meetings. Group leaders recruit new members, assist the group in achieving goals, process difficult feelings and experiences, advocate within the agency and the larger service delivery system, and assist group members in crisis situations.

The emotional themes which emerged over time are discussed and some group process issues are identified. An informal support network has developed among group members as an outgrowth of the parents' group. The authors briefly examine the significance of this development in parents' willingness to increase trust within each other within the group. The parents' group is viewed as a crucial component in the effective treatment of families of adolescents with severe emotional disabilities.

Powell, D.R. (1986). Parent education and support programs. *Young Children*, 41(3), 47-53.

The author summarizes findings of selected studies of parent education and support programs, offering suggestions for program design and for future research. Some of these findings indicate that parents experience short and long term positive effects from participation in parenting programs. The benefits received from participation vary greatly according to parents' socioeconomic status, ethnicity, developmental stages, stress levels, areas of residence, personality, and perception of control over events in their lives. These factors also affect parents' program participation. The author suggests that education and support programs should be tailored to fit parents' specific needs, personalities, and learning styles. He also emphasizes that parents should be appropriately screened and referred to groups to maximize the benefits they receive.

*Powell, T.J. (1979). Comparisons between self-help groups and professional services. *The Journal of Contemporary Social Work*, 60(12), 561-565.

The author interviewed several members of a parent self-help group known as Parents Anonymous to compare their experiences with professional and self-help service systems. Respondents generally felt that Parents Anonymous provided more pragmatic assistance, peer support, confrontation, and satisfaction of basic needs (i.e. transportation, attentive listening) than professional help. Parents also found Parents Anonymous to be easily accessible (physically and emotionally) and highly effective when combined with some form of therapy. The author emphasizes the importance of collaboration and establishing links between professionals and self-help systems.

*Videka-Sherman, L. (1982). Effects of participation in a self-help group for bereaved parents: Compassionate Friends. In L.D. Borman, L.E. Borck, R. Hess, & F.L. Pasquale, *Helping people to help themselves: Self-help and prevention* (pp. 69-77). New York, NY: Haworth Press, Inc.

The death of a child is one of the most significant losses a person can experience. The grief process typically involves varying levels of depression and personal growth. Compassionate Friends is a self-help group that encourages and expects its members to experience their grief thoroughly and for as long as is necessary.

The author presents results of a panel survey study of bereaved parents. A group of 194 bereaved parents were compared for changes in depression and personal growth; the extent of these parents' involvement in Compassionate Friends ranged from none to assuming leadership or group maintenance functions. While no differences in depression were detected, a linear trend was observed in personal growth. Parents who were most involved in the group were more likely to maintain a sense of positive personal change over the one year time span of the study. The impact of self-help group participation may be especially influenced by the positive belief system of Compassionate Friends (i.e. learning to identify some positive outcomes of their losses) and the dynamics of mutual aid. (edited abstract)

*Yoak, M., Chesney, B.K., & Schwartz, N.H. (1985). Active roles in self-help groups for parents of children with cancer. *Children's Health Care*, 14(1), 38-45.

As new diagnostic and treatment approaches for childhood cancer lengthen the duration and chronicity of the disease, parent self-help and mutual support organizations become increasingly important for active coping, social support, and increasing personal efficacy. The authors present quantitative and qualitative data obtained from 43 self-help groups for parents of children with cancer. The data were examined to identify the nature and types of active roles parents assume in these groups. Findings indicate that active roles in self-help groups often emerge at three levels and are not mutually exclusive: interpersonal, in which parents create and sustain one-to-one contacts for mutual support; organizational, in which parents build, lead, and participate in groups; and institutional, in which parents use the self-help organization as a base for advocacy-oriented activities and institutional change. Sixty-eight percent of the parents who responded to the questionnaire had assumed responsibility for planning or facilitating one or more of the following group leadership activities: information and education, emotional support, social and friendship support, fund raising, and initiating changes in the system of care. One of the most prominent themes of this research is that parents experience the greatest benefit from discussing their experiences with other parents in similar circumstances and in giving and receiving help. The article concludes with recommendations for health care professionals. The authors' findings indicate that professionals are most helpful to self-help groups in providing direct support and assistance to parent leadership without imposing some form of authority over the group. (Edited abstract)

SECTION VI: Benefits and Descriptions of Participation in Self-Help Groups and Organizations

SECTION VI: Benefits and Descriptions of Participation in Self-Help Groups and Organizations

*Biegel, D.E., & Yamatani, H. (1987). Help-giving in self-help groups. *Hospital and Community Psychiatry*, 38(11), 1195-1198.

"A longitudinal survey of members of self-help groups for families of the mentally ill in Pittsburgh examined members' perceptions about the types of help-giving activities that took place in the groups and the relationship between those activities and members' degree of satisfaction with the group" (p. 1135). Results indicated that self-help group members generally are satisfied with the benefits of group participation and that social support activities are preferred to more directive activities oriented toward behavioral change. On the other hand, families requiring intensive assistance to learn new behaviors or coping skills are not likely to obtain much satisfaction through participation in self-help groups exclusively.

Gartner, A. (1984). Widower self-help groups: A preventive approach. *Social Policy*, 14, 37-38.

Studies of self-help groups for widows indicate that the mutual aid approach is effective in assisting with the grief process. Widows who participate in self-help groups show less depression, anxiety, somatic symptoms, and psychotropic drug use and higher self-esteem than non-participants. However, a greater number of self-help groups for bereaved spouses are oriented toward women than men. Consequently, men seldom participate in such groups or drop out soon after joining. The author contends that men may suffer from widowhood to a greater extent than women. Widowers tend to be more depressed and have much higher rates of alcoholism and suicide than widows. Early intervention is necessary to minimize the isolation and loneliness widowers often experience and to decrease the risks to their physical and mental health. The author suggests that all-widower self-help groups be developed.

*Lieberman, M.A., & Videka-Sherman, L. (1986). The impact of self-help groups on the mental health of widows and widowers. *American Journal of Orthopsychiatry*, 56(3), 435-449.

They Help Each Other Spiritually (THEOS) is a national organization which provides assistance and support to widows and widowers through local chapters. The authors recruited a study sample of 466 widows and 36 widowers from lists provided by 71 THEOS groups. These individuals were studied over a one-year period to determine the effect of self-help group participation on mental health. THEOS group participants were compared to individuals who sought psychotherapy and to those who did not seek formal assistance. Most THEOS group participants reported improved mental health status over the one year period, but only the participants who made social connections within the group and attended group meetings experienced a significant amelioration of distress. The authors suggest that the passage of time alone does not result in major positive changes in mental health; a particular type of self-help group involvement (commitment and social connection) is necessary for maximum therapeutic benefit.

*Maton, K. (1988). Social support, organizational characteristics, psychological well-being, and group appraisal in three self-help group populations. *American Journal of Community Psychology*, 16(1), 53-77.

The author presents results from a study of three self-help organizations (The Compassionate Friends, TCF, Overeaters Anonymous, OA, Multiple Sclerosis, MS). He examined the relationships between six variables of self-help and perceptions of 144 group members regarding their sense of well-being and satisfaction with their groups . A greater sense of well-being and more positive group appraisal was reported by group members who provided and received support, as compared to those who were primarily recipients of group support. Development of friendships between group members was associated with reports of greater self-esteem and perceived group benefits. Some members of groups with decentralized leadership (i.e., shared between members) reported lower levels of depression and higher self-esteem than participants in other types of groups. Members who perceived a high level of group order and organization were often found to be in the same groups as members who reported receiving more benefits from the group.

Specific variations in responses from members of different self-help organizations are discussed. For example, MS group members perceived fewer benefits and less satisfaction with their groups than CF and OA members. In addition, MS group members perceived less group order and organization, role differentiation, and capable leadership. The author also makes suggestions for areas of future research.

Powell, T.J. (1987). *Self-help organizations and professional practice*. Silver Spring, MD: National Association of Social Workers, Inc.

This book utilizes social science concepts to describe and analyze the attributes, components, and behavioral processes of self-help organizations and their relationship with two other major systems of human service--the professional help system and the informal, community caregiver system. Professional and informal systems of human service intervention (such as self-help and community care) continuously interact and have the potential to be complementary or adversarial. The author provides a comparative analysis of the three systems and offers suggestions for their improved integration.

Reissman, F. (1985). New dimensions in self-help. *Social Policy*, 15(3), 2-4.

The author contends that professional organizations and self-help groups differ in their descriptions of help and their understanding of the nature of the help they provide. These differences are contrasted according to professional and self-help ideologies. As a critical component of self-help groups, the concept of empowerment is discussed in detail. The author also discusses politically-oriented activities of different types of self-help groups, such as advocacy, legislation, and anti-government, pro-community, and "bottom-up" helping approaches.

*Salem, D., Seidman, E., & Rappaport, J. (1988). Community treatment of the mentally ill: The promise of mutual-help organizations. *Social Work*, 33(5), 403-408.

People with chronic mental illnesses are often inadequately prepared for independent community living and therefore need programs that involve individually-tailored long-term support. The authors present their observations over a five-year period of GROW, which is a mutual-help organization providing support to people with chronic mental illnesses with minimal dependence on financial resources or professional leadership. GROW has three program components: weekly group meetings, literature, and a caring social community. The most unique aspect of this organization is its strong emphasis on building friendship networks through formal structures and informal social contacts. GROW is available as a long-term resource and provides continuous (24-hour) and varied sources of support. Members' progress is evaluated through a 12-step process of personal growth. In addition, group involvement changes to meet individuals' different needs. Professionals' roles include serving as a referral source, a liaison between professional and self-help organizations, and a consultant or advocate.

Self help Reporter: The newsletter of the National Self-Help Clearinghouse. New York, NY: City University of New York, Graduate School and University Center, c/o National Self-Help Clearinghouse (33 West 42nd Street, New York, NY 10036).

This newsletter is published quarterly and is available for a modest subscription fee. Useful information is provided information on various aspects of self-help, such as the role of professionals, the private sector, and government in self-help; assessment and progress of the self-help movement; minority involvement; specialized self-help groups and the issues that affect them (i.e., women, ex-fundamentalists, addicts); and, information about conferences, literature, research, and new groups and projects. For further information about the newsletter, write to the above address in care of the Editor.

Other services of the National Self-Help Clearinghouse include training/technical assistance, research, information and referral, self-help presentations to professional and public-policy groups, and publishing.

Shulman, L. (1986). The dynamics of mutual aid. *Social Work With Groups*, 8(4), 51-60.

In this article, social work groups are considered as mutual aid systems; as group members help an individual with a specific problem, the members simultaneously help themselves with similar difficulties. A crucial role for the group leader is to increase and enhance group members' capacities to help one another. The author describes nine of the many different forms of mutual aid. The first process involves sharing ideas, advice, facts, beliefs, observations, and resources to provide opportunities for feedback from other group members. Another form of mutual aid involves discussing "taboo" thoughts or feelings to facilitate the healing process through recognizing the similarity in problems and emotions shared by group members. Giving emotional support is a form of mutual aid which is often as healing for the individual giving support as for the recipient. However, the effectiveness of support is limited without mutual demand or the process of confrontation. Mutual expectation is linked to mutual demand.

When an individual has received support, advice, and opportunities to practice new skills, other group members may expect that person to take action and share the experience at the next meeting. Another very important function of mutual aid is problem-solving; the creativity and support of group members can provide a sense of power to overcome obstacles and accomplish difficult tasks. The author asserts the importance of remembering that mutual aid does not occur spontaneously and requires effort and commitment from group members and leaders.

Spiegel, D. (1982). Self-help and mutual-support groups: A synthesis of the recent literature. In D.E. Biegel & A.J. Naparstek (Eds.), *Community support systems and mental health: Practice, policy, and research* (pp. 98-117). New York, NY: Springer Publishing Company.

In the final section of Part I (Theory and Research), the author presents a comprehensive and systematic review of professional literature related to self-help and mutual aid. Noting the deep historical underpinnings of self-help, [the author] discusses the important roles that such groups perform in assisting individuals to cope with life stresses. He notes that there is general consensus by professionals that self-help is an important and complementary approach to mental health and health services. Although there is a vast descriptive literature in the self-help area, [the author] notes that there are too few scientific studies evaluating the effectiveness of self-help groups. However, the few studies that do exist indicate that self-help groups can indeed be effective. He supports the call by M. Killilea and other self-help experts for further scientific research in this important area. (Edited abstract)

*Young, J., & Williams, C.L. (1988). Whom do mutual-help groups help? A typology of members. *Hospital and Community Psychiatry*, 39(11), 1178-1182.

A total of 1,677 members of the mutual help organization GROW were surveyed regarding their reasons for joining GROW and their perceptions of its effectiveness in meeting their needs. Thirty years ago, the organization was founded to enhance the rehabilitation of former mental patients, but now includes members who have never been treated for mental illness. Cluster analysis of the survey data revealed five distinct groups of members; each with different needs: symptom relief, a supportive community, recovery from trauma, coping with bereavement, or the opportunity to help others. The interests of different types of members in GROW and other mutual-help organizations may be at odds because some may need social support that encourages change (facilitative support) while others may need social support that provides stable relationships (palliative support). (Article abstract)

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Developing and Maintaining Mutual Aid Groups
for Parents and Other Family Members:
An Annotated Bibliography

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